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Chapter 15

Regulating the provision of donor information to donor-conceived children: is there room for improvement?

Author: John B. Appleby

Introduction

One of the most contentious debates in the field of reproductive donation is centred on the question of what information donor-conceived (DC) persons should have about their gamete (sperm and egg) or embryo donors.¹ On the one hand, if regulators provide too little information about donors there is a risk that they will frustrate a range of possible interests held by DC persons. On the other hand, if regulators agree to provide too much information about donors they risk, for example, alienating donors as a result of violating their privacy interests. Furthermore, questions also exist about how and when donor information should be provided.

This chapter attempts to clarify and respond to this regulatory debate by discussing the two main categories of donor information that can be provided to DC persons: non-identifying information and identifying information. The following questions are asked in relation to each category of information: (1) what can the available evidence tell us, if anything, about the information that DC persons want and why regulators should (or should not) provide it; and (2) is donor information being provided effectively or is there room for

¹ From here onward the term 'DC' will generally refer to any person conceived via donated sperm, egg, or embryo.

regulators to make improvements? The discussion that follows from these questions is generally framed in this chapter according to the context of UK regulation; however, comparative examples are drawn from international contexts and the issues at the heart of this discussion are relevant to regulatory contexts beyond the borders of the UK.

In response to the above questions, it is argued that while UK regulators appear to provide non-identifying donor information to DC persons in reasonable quantities and in an effective manner, the same cannot necessarily be said about how regulators currently provide identifying donor information. In contrast, the right amount of identifying information appears to be provided to DC persons by regulators, but the process by which this information is provided appears to be fundamentally flawed. Therefore a recommendation is made for regulators in the UK to allow the release of identifying donor information to parents from the outset of the DC child's life, rather than maintain the status quo of solely restricting the release of such information until DC persons may request it at the age of eighteen. According to this recommendation, parents should be in control of how and when (if ever) identifying donor information is released to their DC children. The early release of identifying donor information to parents would ensure that this information is more likely to be accurate and more likely to be in the interests of children, which appears to be more in line with the regulatory spirit of requiring open-identity donation in the first instance.² It is important to acknowledge that the interests of parents and their offspring are often intertwined; however, the discussion in this chapter is primarily focused on how changes to

² In this chapter the term 'disclosure' refers to the process of informing children that they were donor-conceived. Someone has been disclosed to once they understand that they were donor conceived. The question of whether or not parents should disclose to their DC children is separate (although related) from the arguments put forward in this chapter. Instead, this chapter starts from the basic position that some DC children have been disclosed to or will be disclosed to, and it is these DC persons that are the focus of the chapter.

the provision of donor information could be made to better satisfy the interests of DC persons.³ To begin, a brief summary is provided of the main types of gamete donors that typically exist and the information they provide for DC persons.

Types of donors and what donor-conceived persons can find out about them

The information that DC persons can find out about their donors typically depends on the type of donor that their parents used. For this reason, much of the debate about what kind of information DC persons should have about their donor, is rooted in a related debate: what types of gamete donors should regulators permit? Generally speaking, there are three types of gamete donors: ‘anonymous’, ‘open-identity’, and ‘known’. The donor types are described in this instance according to the regulations set out under the Human Fertilisation and Embryology Act 1990 (as amended 2008).

Individuals conceived with anonymously donated gametes may have access to a range of non-identifying information about their donors. For example, in the UK, at the age of sixteen, donor-conceived children can contact the Human Fertilisation and Embryology Authority (HFEA) to find out non-identifying information about their donors (HFE Act 2008: §31ZA). This information includes: a physical description (i.e. weight, hair colour, eye colour and height); their ethnicity; the year and country of their birth; if they had any children at the time of donation; and possibly additional information, such as a pen portrait and their reasons for donating (HFEA, 2011).⁴ However, the HFEA also explains that although the above

³ This chapter does take into account the interests of parents, but for a more detailed discussion of parents’ interests and perspectives on the provision of donor information see Zadeh et al., Chapter 14.

⁴ A pen portrait can also simply be referred to as a ‘description of yourself’. There are typically no limits with respect to the kinds of information that can be provided in pen portraits; however, if they are being

donor information may be available to some DC persons conceived with donations made between April 1, 1991 and April 1, 2005, donors may not have provided all of this information to clinics in every case (HFEA, 2011).⁵

Those individuals who were conceived with gametes from an open-identity donor will likely receive similar information to that of someone who was conceived with an anonymous donation (as outlined above). However, someone conceived with an open-identity donor will also be able to access identifying information about their donor. Persons conceived with donations made after April 1, 2005 are eligible to request identifying information about their donors from the HFEA when they turn 18 (HFEA 2004; HFE Act 2008).⁶ The identifying donor information that is available from the HFEA includes: name and last known address (HFEA, 2012a). Also, some additional non-identifying information is also made available by the HFEA about open-identity donors, including: the gender of their children if they have any at the time of the donation; marital status; medical history; and possibly a goodwill message to the children conceived with the donation.

‘Known’ gamete donors are a third group of donors that exist. These donors might be friends, family members, or anyone who is known (identifiable) to the prospective parents. What distinguishes known donation from open-identity donation is that the parents know the identity (often very well) of the donor and therefore have access to a potentially broader

requested for anonymous donation, then any description provided would need to exclude identifying information.

⁵ In contrast, the US has no legally binding requirements for fertility clinics to provide any particular pieces of information about donors (including anonymous donors) to DC children or their parents. Nevertheless, many US fertility clinics provide parents and children conceived with anonymous donations with similar amounts of information to that which the HFEA has aimed to provide to UK children conceived with anonymous donors (see Glennon, Chapter 3).

⁶ The use and market demand for open-identity donation has also increased in the US (see Glennon, Chapter 3).

range of information about them from the outset of their agreement to donate. Furthermore, if parents disclose to their children, the children will have additional information about their donors which may be of interest to them. However, if a known donor is used, parents in the UK do not have a legal obligation (as in all cases of donor conception) to disclose to their children; thus, donors of this type will always be known to parents, but (as with all forms of gamete donation) will not necessarily be known by their DC children.

The provision of non-identifying donor information to donor-conceived persons

In the regulatory context of reproductive donation, non-identifying donor information often represents a baseline or common-currency of information that DC persons can likely expect to receive about their donors; or at least this is often the case in most countries (e.g. UK, Belgium, and Denmark) where donation is regulated and some information is collected from donors and made available to DC persons. As outlined above, in the UK the HFEA makes a range of non-identifiable information available to DC persons when they reach the age of 16.⁷ In addition, at any time parents can apply to the HFEA to receive all of the non-identifying information on record about their DC child's donor (HFEA, 2012b). According to the HFEA website, '[t]his is because parents are seen as guardians of their children's interests and are in the best position to pass information on to their children at an age when they can understand it' (HFEA, 2012b). Therefore, DC persons could potentially have access to a range of non-identifying information about their donor from an early age if their parents wished to make it available to them.

⁷ However, the HFEA only began keeping records of birth in licensed clinics from August 1, 1991. Therefore, the HFEA cannot guarantee the provision of any information about donors from before that time.

What is known about the kinds of non-identifying donor information that DC persons wish to be provided with? There is only a very limited amount of empirical evidence available that sheds light on which pieces of this information are important to DC persons (see Blake et al., Chapter 13) and the majority of this evidence is drawn from the context of sperm donation. A recent report by the Nuffield Council on Bioethics (2013) reviewed evidence on the preferences of DC persons towards having different kinds of information about their donors. The report's findings suggests that there is a plurality of views among DC persons about which pieces of non-identifying donor information matter to them. For example, some DC persons place more value on having physical and medical information about their donors. Meanwhile, other DC persons appear to value information about the donors' families and their motivations for donating. Given the limited evidence that is available (especially from the context of egg and embryo donation), it is difficult to argue that either too much or too little non-identifying donor information is currently being collected in the UK by licensed clinics and subsequently being made available by the HFEA to DC persons.⁸

There will inevitably be some additional pieces of non-identifying information that some DC persons may want to have, but which are not currently requested from donors by clinics. For instance, there is a small amount of qualitative evidence which suggests that some DC persons wish that UK regulators would expand the categories of information that would be mandatory for clinics to collect about donors (Nuffield, 2013). Some of the additional categories of information that were suggested, include the donor's financial status, sexual orientation, hobbies and motivations for donation (Nuffield, 2013: 66). While pieces of donor

⁸ Given the overall shortage of evidence on this topic, it would also be difficult to say whether or not too much or too little non-identifying donor information was being offered to DC persons in most countries, beyond the UK.

information such as these may be important to some DC persons, it is not clear that donors should be required to provide them. Any proposal to increase the amount of information that donors are required to provide would likely need to be based on a robust foundation of empirical evidence.⁹ However, at this time insufficient evidence exists to motivate any policy change towards making additional donor information available to DC persons. Instead, the breadth of information aggregated from donors could potentially be increased in a more straightforward way: clinics could do more to encourage and help donors voluntarily provide additional information about themselves (e.g. in a pen portrait) at the time of donation. By gathering as much information as donors are willing to provide, clinics could increase their chances of satisfying the varying preferences future DC persons might have about knowing a range of different facts about their donors.

In fact, the provision of non-identifying donor information to DC persons appears to be relatively uncontroversial. There is little evidence to suggest that there is much discontent among DC persons, DC parents, or donors about the amount of this information that is currently provided in the UK. Similarly, there appear to be few issues with the way this non-identifying information is provided to DC persons (as well as their parents).¹⁰ In contrast, I now turn to the provision of identifying donor information to DC persons, which is more problematic in several respects.

⁹ If we assume that policy makers are generally interested in serving the interests of DC persons, then the above requirements for empirical evidence (with respect to motivating policy change) would need to demonstrate that offering DC persons additional pieces of donor information would be important for the sake of their interests.

¹⁰ Here I am only referring to DC persons who have been disclosed to. Of course, it remains possible that DC persons would like more information, but at this point in time research is scarce with respect to this particular topic.

The provision of identifying donor information to donor-conceived persons

As explained earlier, in addition to the provision of non-identifying information, some countries¹¹ such as the UK, now require that identifying information about donors be made available to DC persons at the age of eighteen; however, the provision of such information remains controversial. Some (Wincott and Crawshaw, 2006) argue that children have a right to such information and that it is generally in their interests to have it. Others are of the view that such regulations infringe on the privacy of donors (and their families) (as discussed by Pennings, 2012), that it possibly reduces the number of potential donors, and that DC persons probably do not really need to have identifying information about their donors anyway. The challenge is making sense of these conflicting views in order to determine the most coherent way of regulating the provision of donor information.

What can the available empirical evidence tell us about the interests that DC children have in obtaining identifiable information about their donors? As Blake et al. have explained in Chapter 13, there is only limited evidence on the views held by DC persons about accessing identifying information about their donors in the future and much of this evidence is about sperm donor-conceived persons. At this point in time it is also impossible to know how many DC persons conceived after April 1, 2005 in the UK will likely want to contact their donors when they turn eighteen (this will not be until at least 2023). However, the evidence¹² that is currently available indicates that there are at least some DC persons who are curious about the identities of their donors and will want to access identifying information

¹¹ Other examples of countries include: Switzerland, Sweden, Austria, The Netherlands, The Australian State of Victoria, and New Zealand. See Blake et al., Chapter 13.

¹² This evidence consists of some quantitative studies and small qualitative studies (primarily about sperm donation), as well as relevant observations from adoption research. For full details see Blake et al., Chapter 13.

about them in the future. What follows is a short summary of some of the key points from the relevant evidence presented and discussed by Blake et al. in Chapter 13.

Much of the available evidence can be drawn from a small US study ($n = 29$) by Scheib et al. (2005) of adolescents conceived with open-identity sperm donors. This study found that most children were interested in finding out the identities of their donors when they reached eighteen. Many children wanted to learn more about their open-identity donors, for reasons such as: discovering what they had in common; learning medical related information about the donor; finding out about their ancestry; general curiosity; wanting to form a friendly relationship or father--child relationship; and, discovering information about and potentially meeting any donor siblings they had. These findings are not necessarily surprising, as Blake et al. (Chapter 13) point out that the adoption literature does show similar patterns of adopted children who express an interest in finding out the identities of their biological parents and who also have a desire to potentially meet them as well.

There is also limited evidence to suggest that parents have an interest in using open-identity donors. Some evidence suggests that parents may be more likely to disclose to their child if they have an identifiable donor (either known or open-identity) as opposed to an anonymous donor. As Blake et al. (Chapter 13) have explained, a study by Scheib (2003) ($n = 45$) on families with open-identity sperm donors reports that most parents felt positive about their donor choice. The Scheib (2003) study also reported that DC children in these families would likely want to contact the donor in the future. For example, a website called the Donor Sibling Registry, based in the US, exists to help connect DC persons with donors and donor siblings. The website has an approximate membership of 40,000 parents and DC children (see Blake et al., Chapter 13). The presence of such high membership numbers (many members are from lesbian or single mother families) since the website's establishment in

2,000 suggest that there is a considerable level of interest among children conceived by anonymous donation and their parents, to identify and learn more about donors.¹³

In addition, some studies have shown that the use of open-identity donors may reduce the risk of DC persons suffering psycho-social harms (e.g. stress, anxiety, and distrust in others) as a result of late or accidental disclosure (Blake et al., Chapter 13; Turner and Coyle, 2000).¹⁴ However, there is also a possibility that DC persons could suffer psycho-social harms (e.g. sadness, disappointment, and rejection) as a consequence of any negative experiences they may have when making contact with donors. Nevertheless, as emphasised in Chapter 13 by Blake et al., the current consensus is that disclosure to DC persons at an early age is usually in the interests of children. This is a position held by both the HFEA (2014b) and the Nuffield Council on Bioethics (2013). Evidence discussed by Blake et al. (Chapter 13) indicates that parents who use anonymous donors may be less likely to disclose to children in order to save their children from the frustration of not having identifying information about their donors; thus, these DC persons would be at risk of accidental disclosure and possibly suffering any psycho-social harms that could follow-on from such an incident. Therefore, the use of open-identity donors and the availability of identifying donor information to DC persons appears to also be advantageous because it increases the likelihood of disclosure and further minimises the possibility of psycho-social risks to the welfare of DC persons.

Having outlined the available evidence, what can be said about the way in which regulators in the UK, for example, go about providing identifying information about donors to DC persons and their families? To begin, the UK's regulatory shift from requiring the

¹³ It should also be noted that there are certainly plenty of DC persons out there who have no interest in their donor and who never will have any interest in their donor.

¹⁴ 'Late' in this instance refers to disclosure after early adolescence.

provision of non-identifying to identifying information about donors from April 2005 onward appears to be rooted in the desire to protect the interests of DC persons. Several events in particular are reported to have contributed to this change of law. The first is that the British Association of Social Worker's Project Group on Assisted Reproduction (Progar) and the Children's Society had campaigned for DC children to be given access to identifying information about their donors, in the same way that adopted children at that time already had access to identifying information about their biological parents (Wincott and Crawshaw, 2011; Nuffield, 2013: 22). This campaigning helped to trigger the UK Department of Health's 'Donor Information Consultation: Providing information about gamete or embryo donors' (2001). The consultation sought '...the views of the public and professionals as to whether, and to what extent, information about people who have donated sperm, eggs or embryos should be given to offspring born as the result of those donations' (DH, 2001: 1).

While the Department of Health consultation was taking place, a case was brought to the courts by a DC child (EM) and a DC adult (Joanna Rose). Both Rose and EM were conceived prior to the establishment of the HFEA and the HFE Act 1990, and argued under the Human Rights Act 1998 (HRA 1998) that they had a right according to Article 8 of the European Convention on Human Rights (ECHR) to non-identifiable information about their donor (Rose v. Secretary of State of Health, 2002). Article 8 states that: 'Everyone has the right to respect for his private and family life, his home and his correspondence' (ECHR). The resulting judgement for the case found that Article 8 was engaged and that a case could be made under the Human Rights Act 1998 to contest whether or not donors have the right to maintain their anonymity (Rose v. Secretary of State of Health, 2002; Nuffield, 2013).

Both the Rose case and the 'Donor Information Consultation' contributed to the Department of Health proposing a change to regulations which ended donor anonymity and

ensured that DC persons would be provided with identifying information about donors in the future. As a consequence, new HFEA regulations were approved in 2004 and came into effect on April 1, 2005 (HFEA, 2004).¹⁵ Importantly, all of the above events illustrate that the desire to protect the interests of DC persons was one of the central motivations behind the Department of Health reforming the HFE Act 1990 to require that identifying information be made available to DC persons. In addition, the empirical evidence outlined above appears to support the UK's use of open-identity donors to protect the interests of DC persons.

However, some important questions remain about the use of open-identity donation and whether or not there is room for improvement in the way that Parliament makes identifying information about donors available to DC persons.

Some of the most common criticisms of open-identity donation are that it has resulted in a decrease of donors in the UK and that it violates the privacy rights of donors and their families (Turkmendag et al., 2008). The first criticism can be rejected based on the statistical evidence that the HFEA makes available about donor numbers. While some previously anonymous donors may not have been interested in continuing to donate in the UK as open-identity donors after April 2005, the figures suggest that the numbers of new (identifiable) donors actually grew in the years following the removal of anonymity (HFEA, 2014a). The second criticism that the removal of anonymity violates the privacy rights of donors can also be rejected. This criticism is not valid because the removal of anonymity in the UK was not retroactive and therefore any donors who provide gametes after April 1, 2005, must as a legal condition of their donation, consent to the potential release of their identifying information to DC persons. If a potential donor feels that the release of their identity to future DC persons

¹⁵ The HFE Act 1990 was later amended in 2008 to include the regulatory changes that were adopted in 2004.

would be a violation of their privacy, then they can choose not to donate.¹⁶ While these criticisms often dominate the debate about using open-identity donation, more pressing questions exist about whether or not identifying donor information is being properly kept up-to-date by the HFEA and why identifying information is only made available to DC persons at the age of eighteen?

UK regulators introduced open-identity donation because it was seen to be in the interests of DC persons to be able to find out accurate and identifiable information about their donors, and to have the means to possibly make contact with them at some point in time. However, as the law stands, DC persons do not enjoy any benefits of having identifiable donor information until they are eighteen years old. This means that identifying donor information is inaccessible to DC persons for the duration of their childhood and during this time they are treated the same way as a DC person with an anonymous donor. One would therefore imagine that Parliament has decided that there are good reasons for withholding identifiable donor information from DC persons until adulthood.

One reason for withholding identifying information about donors until DC children turn eighteen is so that these DC children do not disrupt the stability and functioning of their DC families as a result of trying to make contact with their donors. The root of this policy appears to be found in long-standing adoption laws from across the UK. Since 1975, at the age of eighteen, adopted children in England and Wales have been able to request copies of their birth certificates¹⁷ (Adoption Act 1976; Adoption and Children Act, 2002; Children Act

¹⁶ It is beyond the scope of this chapter to debate whether or not the removal of donor anonymity violates a more general overarching interest (which some may feel is a right) held by some persons to be able to donate without revealing their identity.

¹⁷ For an extensive history of the role and significance of the birth certificate in England, see Edward Higgs' (2011) book titled *Identifying the English: a History of Personal Identification 1500 to the Present*.

1975; Children Act 1989).¹⁸ Similarly, since 1987, adopted children in Northern Ireland have been able to request their birth certificates (The Adoption [Northern Ireland] Order 1987), and Scotland has allowed adopted children to request their birth certificates from the age of 16 since the introduction of the Adoption of Children (Scotland) Act, 1930 (this act was amended and later repealed, and the current law is the Adoption and Children [Scotland] Act, 2007). Policies limiting adopted children's access to their birth certificates until a later age (i.e. sixteen or eighteen years old) were typically put in place to ensure that the identities of genetic parents were kept secret. UK law has attempted to maintain a period of secrecy during the early years of the adoptive child's life because, historically – and especially in the 1960s – there was a desire to encourage the permanence of families with adopted children by minimising any chance of disruption that could be caused by the adopted child searching for his or her genetic parents (at least during the formative years of the child's development) (Bainham, 2005). In this era (e.g. the 1960s and 1970s) experts working in adoption also believed that by around the age of eighteen, adopted persons would probably be mature enough to psychologically and socially cope with making contact with their birth parents (Baran and Pannor, 1993, Carp, 2000).

Based on the research that has taken place since the 1960s we now know that best practices in adoption, as in donor conception, recommend disclosure of adoption to children at an early age (see Blake et al., Chapter 13). Adoption law has not changed to allow access to birth certificates earlier in the child's life, but it is now more common for families to disclose at an early age and to keep their adopted children in touch or aware of their

¹⁸ However, under section 60 of the Adoption and Children Act 2002, it is possible for the High Court to veto this request if it is felt that there are reasonable grounds not to allow an adopted person to receive their birth certificate. One such reason could be that it would be harmful to the original family who put the child up for adoption.

biological parents when possible. When new UK regulations were put in place in 2004 (HFEA, 2004) to abolish anonymity and to allow DC children access to identifying information about their donors at the age of eighteen, it brought the law in line (to some extent) with current adoption law (Wincott and Crawshaw, 2006). However, bringing the amended HFE Act 1990 in line with adoption law appears to have imported and perpetuated a vestige of outdated thinking about children's welfare – namely that allowing DC children to find out identifying information on their donors prior to the age of eighteen, could have a negative impact on the functioning of families.¹⁹

Some might argue that it is important to withhold identifying donor information from parents so that it is not passed on to their DC children, because early contact (by DC children) with donors (i.e. before the child reaches the age of eighteen) may be problematic.²⁰ One could imagine how it might be different and in many ways more complicated for a DC person to make contact with their donor at the age of ten rather than the age of eighteen (or even sixteen). For example, it could be traumatic for a DC person (especially at a young age) to go about contacting and meeting a donor, or the information could be a lot for DC persons to

¹⁹ As a consequence of this discussion, the question does arise about whether or not adoption law (such as the Adoption and Children Act 2002) should also be amended to improve the legal rights that adopted children and their adoptive parents, have to access birth records. However, the socio-legal context of adoption is in many ways different from the socio-legal context of assisted reproduction (e.g. unlike adoption, babies born through gamete donation are typically raised by the same family that they were born into) and it is beyond the scope of this chapter to investigate and engage in debates about revising adoption law. Nevertheless, it is worth keeping in mind that although it has become customary for many adoption agencies to facilitate contact and information sharing between birth parents, adoptive parents and adopted children (often before the child is eighteen years old), these are not practices in which adoption agencies are required by law to engage (Bainham, 2005). Adoption agencies typically engage in such practices because they are understood to be in the interests of adopted children. For a detailed and critical discussion of the law related to information sharing in the context of UK adoption, please see Bainham (2005).

²⁰ This worry was also discussed by the Nuffield Council for Bioethics (2013).

deal with; however, it is only reasonable to expect that a child's parents would help them to manage their expectations and actions, in relation to the donor's information, and would oversee any contact with donors. Parents would also need to ensure that their children were given appropriate counselling and support. In short, the parents of DC children should take age-appropriate actions to protect and assist their children through the experience of making contact with donors, much in the same way that parents would normally be expected to help their children engage and cope with any sensitive social situation. Once these practical measures are recognised and put in place by parents, it appears that it would be reasonably safe and responsible for DC persons younger than eighteen years old to be allowed to make contact with donors. After all, it is important to remember that known donors are currently allowed under UK law and DC persons often make contact with known donors with the assistance and oversight of their parents. Moreover, nobody ever claimed that making contact with a donor from the age of eighteen onward would be easy for DC persons either, and adequate counselling and support should be given to DC individuals seeking contact at this age (and beyond) as well. If an open-identity donor takes issue with the idea of their donor offspring getting in touch with them, then they should probably never have become a donor in the first instance.

There is no clear benefit to the UK's policy (or those like it internationally) of not releasing identifying donor information until DC children are eighteen. Instead, it would be best if the UK amended the HFE Act 1990 (as amended 2008) so that identifying information was made accessible to DC²¹ persons and their parents in the same way that non-identifying information is currently made available: at the age of sixteen DC persons should be able to request identifying details about their donors from the HFEA and DC parents should be able

²¹ To be clear, again, this generally refers to anyone conceived with sperm, eggs or an embryo.

to request identifying information about donors from the outset of the child's life. This change would ensure that parents maintain control over when their DC children find out identifying information about their donors. In other words, children could find out identifying information about their donors via their parents, but only if their parents wished to disclose. Similar systems of information release are already set up in places such as the Australian State of Victoria, where parents are currently able to place requests to the state for identifiable information about their child's donor (Freeman et al., 2014). It would be surprising if the HFEA disagreed with a proposal along these lines, because after all, as I pointed out earlier, the HFEA website clearly states: '...parents are seen as guardians of their children's interests and are in the best position to pass information on to their children at an age when they can understand it' (HFEA, 2012b).

Two of the main benefits of making identifying donor information available to parents from the outset of DC children's lives are: (1) this information will be left in the control of parents to use and share with their DC children as and when they see fit; and (2) this information will be made accessible to parents at a time when the information is most likely to still be up-to-date and accurate (rather than being released after almost two decades, as the law currently stands).

By giving parents control over the management and release of identifying donor information to their children, the regulators are likely to further benefit the interests of those children. For some parents and DC persons it may be valuable to be able to contact donors and potentially keep in touch before DC persons reach the age of eighteen. In fact, some parents may feel it is important to have identifying information because they want to try and arrange for their children to meet their donors and they may also wish to find out about and meet the donors' children or other donor siblings (see Freeman et al., Chapter 8). Of course,

donor siblings and donors are under no legal obligation in the UK to acknowledge or accommodate any attempts by DC persons or their parents to make contact with them. Meanwhile, other parents may feel that it is important to have access to identifying information about donors early in children's lives so that they can respond to questions the children might have about what the donor's name is or where they are from, for example. Early access to identifying information about donors may help to ensure that some DC persons do not have to experience the frustration of not being able to find out basic facts about their donor up until they are eighteen years of age.

One objection to this proposal might be that it will further deter prospective parents from having DC offspring in the UK if they do not wish for their offspring to find out their donor's identity. For example, one fear might be that this proposed regulatory change could drive more prospective parents abroad so that they can access anonymously donated gametes or embryos. It might also discourage intra-familial donation in the UK, particularly in instances where family members are uncomfortable with the idea that DC persons may discover that they (the family members) are the donors. However, this objection is misplaced because the proposed regulatory changes would still allow parents to choose not to disclose if they wished and DC persons would only have legal access to identifying information about their donors two years earlier than they are at present under the amended HFE Act 1990. In other words, if prospective parents would feel uncomfortable with the idea of having DC children in the UK under the proposal put forward in this chapter, they would almost definitely have the same reservations under the current laws in place in the UK. The proposal put forward in this chapter would not make prospective parents of DC persons any worse off with respect to their offspring being at risk of discovering the identity of their donors.

The purpose of open-identity donation is to make identifying information about donors available to DC persons; however, this may amount to nothing more than an empty promise if the information that is provided by the HFEA is not up-to-date or accurate. Currently, the HFEA does not have a reliable system of keeping donor information up to date and DC persons cannot be sure that the information that they will be able to receive at eighteen is accurate. At this point in time clinics rely on donors to voluntarily offer updates to the information that they initially provided at the time of donation. Over the course of eighteen years it is quite possible that a donor's address or name may change. It is also possible that DC persons could wait eighteen years only to find that their donor is deceased (Blake et al., Chapter 13). The easiest and most reliable way of getting accurate identifying information about donors to DC persons is to make it accessible to parents from the outset of the child's life. This approach would mean that clinics could continue to encourage donors to update the information that is kept on record about them by the HFEA, but the HFEA would not need to overhaul their system of information collection to ensure that all details on record were up to date. Instead, it would ultimately be left up to parents, donors and DC children to make further negotiations about what information, if any, is shared between them. Unless these reforms are made to the way identifying information is provided to parents and DC children, the current UK system of providing identifying donor information will continue to undermine the interests of the DC persons that the law is meant to protect.

Conclusion

This chapter has explored and discussed several central questions in the debate about how regulators should go about providing information about donors to DC persons. When it comes to the provision of non-identifying donor information it appears that the UK's HFE

Act 1990 (as amended 2008) generally results in DC persons and their parents receiving the information they want to know about their donors. There is little evidence to suggest that the way the UK regulates the timing or amount of non-identifying donor information that is provided to DC persons should be changed. However, the way the UK regulates the provision of identifying donor information should be treated as a different matter.

The empirical evidence discussed in this chapter and the chapter of Blake et al. suggests that making identifying information about donors available to DC persons is in the interests of at least some DC persons. The availability of such information may increase the likelihood that some parents will disclose to their children, which is seen by many as being in the interests of children. For example, there is a chance that some DC persons could suffer psycho-social harms if they are disclosed to but cannot subsequently access any identifying information about their donor. Also, it appears that the UK's HFE Act 1990 was originally amended to allow the provision of identifying information to DC persons because such changes were seen to be in children's interests. Common criticisms that the removal of donor anonymity would increase donor shortages or be problematic for families, have been rejected or remain unfounded according to the empirical evidence that is available. It is argued instead that the main problem with the UK's current method of regulating the provision of donor information is that it is only released to DC persons at the age of eighteen. A review of some of the legal history leading up to this change suggests that the idea of only releasing donor information to DC persons at the age of eighteen was likely imported from outdated adoption laws (Baran and Pannor, 1993; Carp, 2000) which have similar provisions that restrict the age at which adopted persons can access copies of their birth certificates. A further problem with the way the HFEA withholds identifying information for eighteen years after the DC child's birth is that the information held on record by the HFEA may very well be out of date by the

time is it accessed. This chapter has therefore recommended that Parliament should amend the HFE Act 1990 (as amended 2008) to allow DC persons to request identifying donor information at the age of sixteen, in addition to the non-identifying donor information they can currently request at this age. It is also recommended that the amended HFE Act should be amended so that identifying donor information is released to the parents of DC persons, upon request, from the outset of their children's lives. This way parents can be in control of managing (e.g. updating the information, using it to contact donors or potentially making contact with donor siblings) and sharing this valuable donor information with their children at the time that they feel is right. In the words of the HFEA, parents are typically best placed to make judgements about how and when donor information is made available to their children. If the HFEA relinquishes control of identifying donor information to parents, then regulators will likely be doing what is in the interests of DC children, which after all, was the main purpose behind making such information available to DC persons in the first place.²²

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